

**COEUR D'ALENE PUBLIC HEARING  
JULY 9, 2009**

**INTRODUCTORY STATEMENT**

Health and Welfare Rules

Docket Number(s):

16-0305-0902– Rules Governing Eligibility for Aid to the Aged, Blind and Disabled (AABD)

16-0318-0901- Medicaid Cost-Sharing (Fee Rule)

Hearing Date: Thursday, July 9, 2009

Location: Department of Health & Welfare

1120 Ironwood Dr. Suite 102

Large Conference Room

Coeur d'Alene, ID

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1           *TIM GERLITZ:* This is a taped hearing. Let the record show that I am Tim Gerlitz. I am a  
2 Program Manager with the Department of Health & Welfare. I am a Program Manager with the  
3 Bureau of Developmental Disabilities and manage Regions 1 and 2, so the ten (10) northern  
4 counties for the DD Program here for the Department. And I have been designated as the  
5 Facilitator by the Administrators for the Divisions of Medicaid and Welfare in the Department of  
6 Health & Welfare. It is 7:00 p.m. on July 9<sup>th</sup>, 2009. We are in the large conference room in Suite  
7 102 at the Regional Office of the Department of Health & Welfare in Coeur d'Alene, Idaho, and  
8 this is the time and place set to receive oral comments, as provided for in Section 67-5222, Idaho  
9 Code, for the proposed rules in the following Dockets:

10           16-0305-0902 - Rules Governing Eligibility for Aid to the Aged, Blind and Disabled (AABD)

1 16-0318-0901-- Medicaid Cost-Sharing (Fee Rule)

2 The purpose of this proceeding is to gather the facts, views, or arguments from all interested  
3 persons relative to the proposed rules so that they may receive consideration by the Department of  
4 Health & Welfare. I will accept written statements or documents at the hearing today, if relevant,  
5 and signed by the persons presenting them. The materials will be included as exhibits in the record,  
6 which I will transmit to the Department's Administrative Procedures Section following the close of  
7 this hearing.

8 Let the record show that the notice of this hearing was published in the Idaho  
9 Administrative Bulletin on Wednesday, July 1<sup>st</sup>, 2009, as required by Section 67-5221, Idaho Code.  
10 This publication was timely made and other necessary notice requirements have been met.

11 As this hearing is an informal proceeding, there is no right to cross-examine a person  
12 offering a comment, nor is there a right to counsel or subpoena. No objections or procedures of a  
13 technically legal nature will be received. As the Facilitator, I am the sole regulator of the course of  
14 the presentations, including, but not limited to, a determination that the comments are outside the  
15 scope of the rule or that comments are unduly repetitious. I would like to emphasize that this  
16 hearing is being held to gather public comments on the proposed rules. It is not a forum to debate  
17 the issues involved in the rulemaking or to conduct a dialogue. This hearing time is reserved for  
18 you, the public, to provide oral comment on the rules.

19 All those interested persons attending this proceeding are asked to sign in on the roster by  
20 the entrance, indicating a desire, if any, to make an oral presentation. After a brief statement made  
21 by the Department of Health & Welfare summarizing the information upon which the proposed

1 action is based, each person will be given an opportunity to speak at least once prior to any person  
2 being heard a second time.

3 At this time, the Department of Health & Welfare's statement will be read into the record,  
4 followed by the oral presentations.

5 As part of the 2010 Medicaid appropriation (House Bill #322), the 2009 Idaho Legislature  
6 gave the Department direction to establish cost-sharing based on ability to pay for families whose  
7 children are eligible for Home Care for Certain Disabled Children (commonly known as the  
8 Katie Beckett Program). The parental cost-sharing requirement will encourage families to take  
9 financial responsibility for a portion of the program cost while allowing Medicaid to focus  
10 limited resources on those families with the greatest financial need. The dockets that we will be  
11 hearing testimony and comment on are the changes to Idaho Administrative Rules to implement  
12 this cost-sharing requirement.

13 16-0305-0902–Rules Governing Eligibility for Aid to the Aged, Blind and Disabled  
14 (AABD). These changes add the requirement for cost-sharing to the eligibility for Certain  
15 Disabled Children section of the rules.

16 16-0318-0901 – Medicaid Cost Sharing (Fee Rule). These rule changes contain the  
17 amount of cost-sharing families will be required to pay to the Department, the consequences of  
18 not paying, and the authority for the Department to pursue collection of delinquent payments.

19 To begin, I will call upon persons, in order, who indicated on the roster a wish to be heard.  
20 Since these proceedings will be recorded, I ask that those who wish to make oral presentations  
21 come forward to the microphone, preceding their comments with their name, and then please

1 spelling your surname.

2 So at this time, I'll move this microphone here to this table. Okay, the first name on the list  
3 is Burt and Karen Wallis. First we have Burt Wallis.

4 *BURT WALLIS:* Yes, my name is Burt Wallis. The last name is spelled W-A-L-L-I-S.  
5 First of all I'd like to say that this is not really a cost-sharing plan. It's more of a tax on families  
6 who have a disabled child in their home. It unfairly targets us, and for people who have decided to  
7 stand up and do the right thing, and take care of their child, and really need a little extra help. I can  
8 also point out that it is not necessarily a very fair thing because, and I don't expect an answer from  
9 this knowing it's not your department, but does the school district intend to follow the same sort of  
10 procedure of fee-sharing with students who might be learning disabled and are requiring extra  
11 services from the school district? Would the school district be interested in billing parents for the  
12 extra services there? So I think that this is really unfairly targeting a group of people who really  
13 need the help.

14 The other thing that I find somewhat curious is that there seems to be a desire to take  
15 parents to collection if they're not paying. Is this really in the best interest of the child at home?  
16 These parents have got problems right now. They've got disabled children with downs syndrome  
17 or whatever, blind, and now all of a sudden we're going to either force them to go bankrupt paying  
18 for these services or force them into bankruptcy trying to pay the fees to the State. Either way, it's  
19 not a very positive thing to be doing to families that already are burdened. It's just, we're adding  
20 insult to injury here.

21 To go back also on the fee-sharing aspect of it. And this may be in your realm too. Is there

1 any plan for Medicaid to be asking for fee-sharing for families who are taking care of elderly  
2 parents who might be taking Medicaid services? They're in the same situation. What's the  
3 difference? I can't see the difference between an elderly parent who needs care and a young child  
4 who needs care and getting services from the State. There is no difference. We're attacking a  
5 group of people here to force them out of the system, I think, for the sole purpose of getting away  
6 with, or abandoning Katie Beckett and ending the program.

7 I read in the docket that there was an expected \$210,000 savings. \$210,000?  
8 What's the State budget? I mean, that's pennies. You know, we could go to any other line item in  
9 the budget and scratch out \$210,000, I guaranty no one would ever miss it. But we're saying it's  
10 going to save \$210,000. At least that's what is in the document. What happens if in the State, one  
11 (1) child, out of this entire State, one (1) child is put into permanent full-time institutional at the  
12 cost of the State? I guaranty the \$210,000 savings is going to turn into a \$210,000 loss overnight  
13 for just one (1) child. What happens, you know, the assumptions that you are making for  
14 determining the \$210,000. What if the parents that are in this 3% and 4½% co-pays brackets all  
15 drop out? Then, you're still going to have to have the collection staff, you're still going to have to  
16 have the people sending the bills out to the parents, making the determinations of what the fees  
17 should be, yet they're only going to be paying nothing or \$15.00 a month. The revenues won't be  
18 there, but you're still gonna have the increased staff to pay for the collections. So now the savings  
19 may not be there either. It may end up costing them. What about parents who drop out of the  
20 system saying, "I can't afford this," slowly drop out and they go through a different route and make  
21 the State pay for everything, instead of in our case, like our health insurance picks up a huge chunk

1 of it. The State is going to end up paying a lot more than this \$210,000 savings that they're talking  
2 about. I don't think that's going to happen.

3 In our own situation here, we're using Katie Beckett resources to provide healthcare and  
4 services to our child to help that person become a productive, useful tax-paying citizen. Without  
5 some of these programs, there's a real chance that they may end up being just a user of the system,  
6 instead of a contributing taxpayer. So, I think this whole system is not a fee-sharing system, it is a  
7 tax on disabled or families with disabled children. I think it is wrong and I think if we're looking to  
8 save \$210,000, we can find it somewhere else. Thank you.

9 *TIM GERLITZ:* Next up, Mrs. Karen Wallis.

10 *KAREN WALLIS:* I'm Karen Wallis, and it's W-A-L-L-I-S. I just wanted to briefly, I know  
11 my husband just spoke so I stick with that also. But I'd like to say as a mom and primary caregiver  
12 of a disabled child, I would like to say that when you talk about the cost-sharing for families, and it  
13 specifies in there that the families that are in the biggest need, we are the families with the biggest  
14 need. I've had to make tough decisions as a mom, that I work part-time. We've had big financial  
15 hits in our family because I'm there for my child. I'm the one that takes care of him. I don't rely on  
16 the State to do it. We finally within the past year just started getting some support from Katie  
17 Beckett because we got to the point where we weren't able to financially do a lot of things that we  
18 really felt our son needed. And we also didn't know what programs were out there even through  
19 the schools and such, that the State coordinator was able to help us. We knew her through the  
20 system. It's really difficult to maneuver through the system without a coordinator a lot of times.  
21 We simply cannot afford this. We are in the 3% bracket. We are middle American and we cannot

1 pay this. We are being taxed to death. We're paying so much. We have a disabled child and you  
2 know, I'm working part-time just so I can do my portion which I feel is important. I think parents  
3 should do their portion, and I feel that to unfairly make us pay more is just wrong. Not only that,  
4 but how are you going to do this? If we have insurance that pays, what happens when we meet our  
5 deductibles and our insurance is paying 100%? Are we still getting those bills? What happens if  
6 we don't have services every month, are you gonna not send us a bill? And then, what if one month  
7 we happen to have had some type of service and they billed late, are you going to retroactively bill  
8 us for three (3) months because the doctors didn't bill on time? I mean, this is kind of a logistical  
9 nightmare in my mind, and I think for parents that already have financial needs, emotional needs. I  
10 don't get respite care. You know, we're dealing with this situation and reality everyday and I feel  
11 it's really wrong to add another burden to our family. Thank you.

12 *TIM GERLITZ:* Next on the list is Jill Smith.

13 *JILL SMITH:* I'm Jill Smith. That's S-M-I-T-H. I'm here as a parent. Some of you know  
14 me. I work in the system as well, but that hat is over here. I'm just here as a parent. I guess to start  
15 with, all of us are unique in this room because each of our situations is very different. I don't think  
16 it's the State's responsibility to subsidize me for having a child with a disability, but I think Katie  
17 Beckett was designed to help keep children in their communities, which is always cheaper than  
18 institutional care. And there's no middle ground. That's a huge gap, and it's getting wider  
19 everyday.

20 My concern isn't necessarily that the State is looking at establishing co-pays. My concern is  
21 how this is being implemented. An interesting thing is that I knew when I received that June 29<sup>th</sup>

1 letter this was going to be interesting, because within less than a week I got my reauthorization  
2 statement saying, “Give us your income information.” I have more time to give public commentary  
3 on this proposal than I have to provide my income information. I only have until the 17<sup>th</sup> of July to  
4 turn it in or I’m delinquent. There’s something wrong with that situation. The State is saying,  
5 “Please give us your comments,” but the train is barreling down the track.

6 My situation is that we require very much a care provider for my son who is almost  
7 seventeen (17) or one of us doesn’t work. The disability environment and typical society are two  
8 very different things. Katie Beckett helps neutralize some of the challenges that we have to just  
9 have the same experiences of any other family. So I don’t think anyone should do a parade around  
10 me because my child has severe epilepsy, but what gets hard and frustrating is that so many things  
11 are just so much harder in this society. Insurance costs more because my child is a risk, so I pay  
12 more because of his situation. I can’t work a 9 to 5 job anymore because I have to be able to get up  
13 and leave. But the fact that we’ve maintained health insurance has saved the State an enormous  
14 amount of money, and the only thing we’ve really asked for is help with the care provider. That is  
15 expensive and it adds up. We could not afford it on our own.

16 Ultimately, I would propose that something would need to stop at this time to do more  
17 information gathering. In Idaho, we’re gathering a lot of information about family-directed services  
18 that’s predicated off self-directed services which has national models and a decade worth of work  
19 has gone into in Idaho. Why not use this year in 2009 and 2010 to sit down with families when  
20 they’re going through their reauthorization and say, “Help us understand what your needs are. Did  
21 you know that there’s a program in Idaho that can help you pay for your premiums if you get



1 commercial insurance? Let's get you on commercial insurance and save the State some money.”  
2 Those dollars invested to do that would save a tremendous amount. A lot of service coordinators in  
3 this area and in this state aren't aware of all of these programs. I'm lucky enough to understand  
4 some of the dynamics with these changes, but a lot of families that would have gotten those two  
5 letters back to back, they would have been panicking. And in fact, I've gotten calls from friends  
6 and colleagues who are completely devastated by this. This is going too fast. Why not build  
7 providers' knowledge of how insurance works, and how to be an astute consumer to help families  
8 become astute consumers of what they're doing, to understand what their costs are. If you're on  
9 Medicaid I any way, shape or form, you don't get a bill. So many families have no idea what the  
10 costs of these services are. And how can they understand then that your co-pay will help offset  
11 these services when they have no idea and never have what those things cost? I just think that using  
12 this year to build information, build the consumer base for families and providers alike, because so  
13 many providers are in the silo of their own making and they don't know what's going on outside of  
14 their own silo, that it would create a thoughtful and responsible set of consumers so we can turn and  
15 help our children with disabilities be thoughtful and responsible consumers of their services. We're  
16 all agreed that the way disability services flow from the Federal government to the State  
17 government is broken. No one debates that. But I don't think you build a broken boat on a broken  
18 keel. I mean somehow you've got to stop and fix what's broken before you move on. Thank you.

19 *TIM GERLITZ:* Next, Sara Garcia.

20 *SARAH GARCIA:* My name is Sarah Garcia. G-A-R-C-I-A. I came to express my concern  
21 about the cost-sharing as distributed, or as communicated to us just last week in the letters. While I

1 understand and appreciate the budget constraints of the State of Idaho, because I am an employee of  
2 a State-funded agency, I do understand the budget constraints that the State is currently facing. And  
3 I do not in principle disagree with the concept of cost-sharing, it's the methodology of cost-sharing  
4 that is based on the gross income of the parents, rather than any other methodology for sharing  
5 those costs.

6 We personally, with our son, only use Medicaid to cover IBI services, which are not  
7 available unless you have Medicaid, and are indeed not even affordable without Medicaid. We are  
8 fortunate to have private insurance, and we are fortunate to have the ability to juggle our income in  
9 order to pay for things that we could be planning for Medicaid at this time. We choose to not get a  
10 prescription for diapers and pay for them ourselves. We choose to buy medical-grade equipment  
11 for him out of our pockets and to juggle our family income in order to do that. If we end up having  
12 to pay 3 or 4% of our gross income in Medicaid premiums in order to provide services for our son,  
13 we will be forced to make a decision. And that decision is either going to be, do we continue to  
14 provide services in order to hope that our son can get out of the system and be an independent  
15 citizen on his own, or do we try to recoup that money by claiming things that we currently are able  
16 to cover. We won't be able to cover those. We won't be able to juggle that difference once we pay  
17 that premium. That premium is larger than the one I pay for my own insurance through my  
18 employer. You know, we try to be responsible citizens and understand that there are people who  
19 are in bigger need than we are, and we feel we're being penalized for having a larger income even  
20 though we don't use as many services. So, I feel that we should really be looking at the  
21 methodology for cost-sharing, rather than just doing a blanket of percentage of income off of

1 parents. You are unduly punishing parents who are barely making it, or parents who are trying to  
2 respect the system and to try to assume some burden of their own in order not to overburden the  
3 system that we're aware is already overburdened. We don't have that \$300-\$400 a month to pay in  
4 premiums. We'll have to find a way to cover it, and that may be making additional claims. And  
5 that's going to ruin the \$210,000 savings that the State is trying to achieve through this process. So,  
6 I urge as the other parents urge to think through this better and to talk to some parents and see if  
7 there are other ways that we can accomplish the same goal. Thank you.

8 *RASHEL PATTEE:* So state my name and spell it? Rashel Pattee. P-A-T-T-E-E. And I'm  
9 from Idaho Falls, Idaho. And I have two (2) children with autism, so this particular ruling affects  
10 me double. We fall into the category of 4½%, which pretty much would be devastating for us. My  
11 children also when we talk about getting services through the school districts and things like that,  
12 they are high functioning enough that they don't qualify for school services. I'm constantly going  
13 to battle for their needs at the school and am being told that they cannot qualify for things because  
14 they function too highly. So, we rely on the Katie Beckett Program for needs of speech therapy,  
15 occupational therapy, developmental therapy. We've had IBI. My husband is a diabetic. He's  
16 blind in one eye. He could currently be disabled. He chooses to work full-time and provide for our  
17 family and do the best we can. I also have health problems and I work outside of the home, but I  
18 am also unable to work more than part-time. Because of the needs of my children, I am constantly  
19 taking them to doctor's appointments, therapy appointments in order for them to progress and be  
20 independent adults. They have a very high potential of being independent tax-paying adults, and  
21 that is what I feel like the Katie Beckett Program is for. I understand that there is need for probably

1 cost-sharing, but the level that is being asked of my family is outrageous. We're talking at least  
2 \$800 a month. So if this goes through, there's great possibility that we will be bankruptcy. And we  
3 are trying the hardest we can to the best for our family. And we've got a double burden. And  
4 without the Katie Beckett Program, my kids would have not progressed to the point they are now.  
5 My two (2) year old could not speak at two. He can speak now and he's very intelligent. He's  
6 seven years old now. Besides the autism they have, they also have partial complex seizures, both of  
7 them. They are on four (4) medications a piece and we have chose not to put them on private  
8 insurance at this time. I am willing to put them on private insurance if that was an option that the  
9 State would consider in all of their considerations of this ruling to help offset costs. I can  
10 understand the reason they need to offset costs, but what you are asking my family is almost  
11 impossible. And then to say that you would, if we couldn't pay, that we would be penalized or  
12 collected upon, and I just know that some other choices would have to be made. Like Mrs. Garcia,  
13 we choose to pay for things out of our pocket too. We choose to pay for diapers when needed. We  
14 choose to pay for things that we could get. So there are things that we use our personal income for  
15 to not burden the State as much. I can understand that our needs as a collective group, the Katie  
16 Beckett families. It's a trial. And we all I feel like are trying our best to do what we can for our  
17 families, to try to be fair to the State. I appreciate what the State does for me. Before I heard of  
18 Katie Beckett, I was at a loss. I did not know what to do for my child. When I first started into this  
19 with my oldest son, I felt like he met milestones and was progressing somewhat normally, but he  
20 was an emotional disaster. I did not know what was wrong with him. And without the Katie  
21 Beckett Program, he would not be where he's at today. And so I feel like this program has been

1 very, very good for us, and I would definitely be willing to put some cost-sharing towards it, but the  
2 amount is just absolutely too much. Thank you.

3 *TIM GERLITZ:* Next is Kristian Carson. State your name and spell the last name.

4 *KRISTIAN CARSON:* Okay. It's Kristian, K-R-I-S-T-I-A-N. And my last name is Carson,  
5 C-A-R-S-O-N. I may not speak as eloquently as others, but I will be direct and honest. I moved  
6 out here to Idaho from Seattle when my son was three (3) years old, not yet diagnosed with autism.  
7 I did it on my own from a divorce, and my ex-husband is not involved in my son's life, doesn't  
8 want to be, and occasionally pays child support. I was a veteran of the United States Navy. I went  
9 to school full-time while raising my son who was then diagnosed with autism. I've done it on my  
10 own. I did not collect food stamps. The only time I collected food stamps was when I had no  
11 money and no health insurance, and I collected I think for two months. I went through school, went  
12 five years of school. I've had to repeat classes several times because I missed things because of my  
13 son. And he's doing phenomenal now. He's doing really well. He got the IBI he needed. And  
14 God help me, how I ever made it I don't know. I did not know a soul when I moved here. I went  
15 and got a job after I was done with my schooling. I lost that job after a few months because of the  
16 demand that I needed to be with my son. He has appointments, doctor's appointments, med-  
17 checks, and I'm the only one if he's sick to pick him up. So, I lost a job because of that. And  
18 thankfully, I had another job that was through the State and I've kept it for two years, and as you  
19 know, the State's getting cuts now too. And I'm the only one, and I've done it without food  
20 stamps. I lived in an apartment, and I was frugal, and I managed. Through the USDA Department,  
21 I've got a house now. Am I living big? No. I'm making it, just like everybody else is. And

1 through my job, I have health insurance for myself and for my son. And I pay things out of my  
2 pocket for him, and I expect to, he's my son. Katie Beckett came along when I was pushed over the  
3 income level because my ex-husband then decided he wanted to pay child support because he  
4 would have faced jail if he hadn't. He's in another state, so then I was left with, "What do I do now  
5 because I have to work and I've got this child who needs care?" So, you know, thank God Katie  
6 Beckett came along and, you know, they would do that cushion for me. You know, he couldn't be  
7 in a regular daycare. He has to have an aide consistently. You know, I'm not living off the hog.  
8 I'm making it paycheck to paycheck. I don't understand how when I'm paying into health  
9 insurance, I am the only parent here, and I feel penalized. You know, I just think that there is a  
10 quick, that this whole thing was done pretty quickly to say, "We need some money, let's pull it  
11 here, and that's that." And I really have to question the logic behind it and where that decision was  
12 made. It's just numbers, I think, to people on paper. And I think really hearing from the parents  
13 and say, "Okay, what are your needs?" You know, "Where do you need that fill?" You know,  
14 maybe they don't need food stamps, but maybe they need some other type of help. My son has to  
15 have medications. If he's not, you can tell in a heartbeat that he's not on it. And they're not cheap  
16 by any means. And I've balanced his medications with good dieting, and I've busted my butt  
17 reading everything about autism, his dieting, and what foods would help what. And I mean, I've  
18 done my part as a parent. I've done everything I can. And I just think this was just a quickie, you  
19 know, "We needed the numbers to crunch. This is where we're gonna take it," without really  
20 sitting back and looking at it and going, "Where are the needs? How can we balance this?" This is  
21 just a quickie, boom, here's your answer submission. I'm just saying that, I think that things could

1 be pulled back, and I think it needs to be reevaluated, and the numbers are high. I mean, I'm just  
2 floored by it. I'm just floored. You know, I'm just really floored. And I've been doing it on my  
3 own. How I'm going to do it the next many years is day by day, you know. I'm just floored. I don't  
4 know how in the world and why this group of people are penalized. Your life is already made of  
5 sacrifices. But you know, I just wanted to say give me a break. I mean, honestly. You know, I just  
6 think that somebody needs a little bit more consideration, and really pull back, and really think  
7 about how this is going to affect the families. That's it. I just wanted to say my part on that. Thank  
8 you.

9 *TIM GERLITZ:* Alright, I ask if anybody who has already testified (*inaudible....*) Susan?

10 *SUSAN VILLELLI:* Yes.

11 *TIM GERLITZ:* You're up next, please. Say your name, spell your last name.

12 *SUSAN VILLELLI:* Sure. Susan is the first name, and the last name is Villelli. V as in  
13 Victor, I-L-L-E-L-L-I. And I put a big question mark down there because I wasn't sure if I'd have  
14 anything to say, and then I thought wait a second, I'm a communicator, of course I do. And I  
15 listened to you guys and I thought ditto, ditto, ditto, yes, yes, yes. I mean, so many things that  
16 these parents have brought up. I didn't have anything, you know, predesigned to say, but I listened  
17 to it and I go, "You're right, this is not something fair to us parents." So, anyway, I'm here on two  
18 behalves. One, is I'm a parent, and second, I started a group for family and friends of people with  
19 downs syndrome because of my daughter. And I got so many calls from people saying, "What is  
20 going on? Can you go to this meeting?" And I didn't know I could until I got my parents to come  
21 watch the kids, and it's, "Yes, I've got to go. I've got to find out what's going on." Because it was

1 out of the blue. I mean, we all went away on vacation and came back and went, "What is this  
2 letter? We don't know what it means." It's kind of like the rug was just taken out from under our  
3 feet, and I had all these parents call me from this group and I'm like, "I don't have the answer, I  
4 don't know. I don't know where this came from. I don't know what it means." And I was starting  
5 down here thinking I don't really have anything to say, I want to learn from this. But the more I  
6 hear people talk, I think this is so, It's unfair to those of us who will not be able to afford it. Who  
7 are right now making ends meet. And, you know, you take a look at this and you think, here's  
8 where my life is going this direction, and now it goes a completely different direction because we're  
9 doing the best to keep our daughter out of the system, and doing everything on our own, and she's  
10 high functioning for the schools again. Kind of what I'm hearing from you guys. Because she's  
11 high functioning, even though she's got downs syndrome, she doesn't qualify for some of the things  
12 in the schools. So, Katie Beckett has helped us keep her high functioning. And now we're saying,  
13 "You can't have Katie Beckett. Good luck." And that's kind of one of those things as a parent,  
14 you're like, "Wait a second, this is the State telling me this? The State telling me it would better for  
15 her to be in the system than at home?" So, I don't understand it. I'm sorry. My goal is not to sit up  
16 here and blubber, but anyway. I want to be the voice of the people in my organization that probably  
17 have the same feeling as I do, that we don't exactly know where this is coming from. The system is  
18 broken, and I know because I talk to so many people just in doing what I do in the community, with  
19 my daughter with therapists, that there are people who abuse the system. I get it. I know there are.  
20 It's not us. It's not all these people sitting in this room. Audit the system. Figure out who the  
21 problem is. If the State really needs to make \$210,000, we'll pay x amount of dollars to help that



1 deficit, but audit the system and make it work right. Find the people who aren't doing the things  
2 right. Find the people who are taking advantage of the system and don't penalize those of us who  
3 are trying to good job. Buying our own diapers, you know, doing things to make sure that the  
4 system is not going to be taken advantage of. I just wanted to make that comment, and you know, it  
5 did really come out of nowhere. For those of us that are sitting here saying, "Oh my gosh, what  
6 does this mean for me." But also, the letter that we got had the wrong address on it. So yeah, I  
7 passed several people who are up on Ironwood Court looking for this building, so I had my husband  
8 at home Google it, and he's like, "No, no, no. Maybe it's Ironwood Drive. I don't know." So I  
9 have been down here 20 minutes before the meeting trying to find where this building was. I know  
10 there's other people still probably looking for the building and giving up. So maybe there's an  
11 option or an opportunity to do this again and have somebody else, have more people come in and  
12 talk, because I know just from the people who've called me or e-mailed me today and said, "Oh my  
13 gosh, I can't make it. They didn't even give me time to get childcare. I've got a child with a  
14 disability. Why in the heck are they giving me 3 or 4 days to figure out how to get to this meeting?"  
15 And then for the people who did find childcare like me almost didn't come. I mean, I was headed  
16 back to Hayden Lake going, "I can't even find it. There's no such thing as 1120 Ironwood Court."  
17 So anyway, I just wanted to make that note that, you know, there might be an opportunity to have  
18 more people comment. I don't know if you want more comments because it would probably be  
19 similar to ours, but I think it would be only fair to give people another shot at it. So, I will stop  
20 now. And I promised that I wasn't going to blubber, but I'm done. Thanks.

21 *TIM GERLITZ: (Partially Inaudible.)* As a reminder too,... picked up on the back table,

1 and there's two dockets... . And then if you take a look at the second page of the ... third page on  
2 the left hand side is an address for Tamara Prisock, DHW – Administrative Procedures Section.  
3 Above that it states anyone may submit written comments regarding the proposed rulemaking... .  
4 In that address... .So if you are unable to..., we do have another hearing scheduled next  
5 Thursday...Caldwell. So, whenever we attend that hearing... . But, do we have anyone else who  
6 has not made comments that ... ? And your name?

7 *LISA FINDLAY:* Lisa Findlay.

8 *TIM GERITZ:* Lisa Findlay.

9 *LISA FINDLAY:* My name is Lisa Findlay, and it's spelled F-I-N-D-L-A-Y. And when we  
10 received the letter, of course it came as a surprise, and what we'll have to do in our family is take  
11 my son of my husband's health insurance so that we can afford the premium for Medicaid now.  
12 Whereas, thousands and thousands of dollars, because my son has high needs, have gone  
13 beforehand, before Medicaid even picked up anything, has gone through my husband's insurance.  
14 And now, we have to make the choice one way or the other.

15 The other thing I wanted to comment on, for years I have been a thorn in the side of our  
16 medical supplier because they double and triple bill for things that we never receive. And if we  
17 would actually receive something in the mail like we do from the commercial health insurance,  
18 that's how I pick up that they are billing for things that we don't receive. Because they'll bill for  
19 say a wheel chair cover over and over again, and we've never received it. So I'll call the supply and  
20 they'll say, "Well, yeah you did. No you didn't." But my point is, is that if we would receive  
21 something on a monthly basis that showed us what's being billed to Medicaid, we could argue the

1 things that have been unfairly billed. The things that have been, and that would save thousands of  
2 dollars, just that alone. Just a couple of points I thought I would point out. Thank you.

3 *TIM GERLITZ:* Anyone else who wants to testify? Did you sign in?

4 *CAMERON CUTLER:* No, I missed that when I came in. I wanted to sign up.

5 *TIM GERITZ:* Go ahead. Say your name and spell the last.

6 *CAMERON CUTLER:* My name is Cameron Cutler. C-U-T-L-E-R. And I'd really just  
7 like to reiterate a few comments that have been made, and I appreciate everyone's comments. I  
8 think it's pretty clear from the parents that are here that are doing their very best to raise their kids,  
9 but also see Katie Beckett as a great help and success in their lives and in the lives of their kids, and  
10 how early intervention or the help that they've received has really helped the momentum and the  
11 capacity of their children to grow despite the circumstances that they're in.

12 We, I knew about this meeting because our son just turned three (3). So, we actually  
13 attended the infant/toddler meeting last month which was also about starting to charge for  
14 infant/toddler services as well, and how the methodology that they were going to do. So I was a bit  
15 surprised for this meeting that it was already decided how it was going to be done, whereas  
16 infant/toddler was testing and asking input from the different areas on how they might go about it,  
17 whether it be from income, whether it be by services, whether it be various different methods of  
18 how they could do it. Where this one came kind of cart blanch was, we're going to do it based on  
19 income. And my concern there, as has been voiced several times here, is that by doing it strictly off  
20 of an income level, I see the potential for people who have a disparity in services. I know just from  
21 a friend that I have, and I apologize for (*inaudible*) around, who has a son who's also on Katie

1 Beckett, that receives quite a bit more in terms of services a month. Whereas, if I wait that out and  
2 said okay, "Well, he's paying the same amount as I would be roughly," I could see how this system  
3 could be abused very quickly in that, "Well, I'm paying an amount. I'm entitled to whatever  
4 services under that amount." So I'm going to start looking for other things to, would in turn burden  
5 the State with more costs because I'm paying a premium now. Whereas, we have grown up and our  
6 philosophy has been, and our service coordinator has been very helpful in the sense to we always  
7 wanted to have quality over quantity and to always be able to where we can foot the bill. But in  
8 some cases it's just not possible. But I feel that the way of the direction this is going without being  
9 thought through properly is that it will make us think, "What else can I do? I'm now having to pay  
10 for this. So I'm going to start looking for other things." And it could turn into abuse in some cases  
11 for people who aren't responsible.

12 I'm also concerned that in our case, where I run a small business and we have private  
13 insurance but it's on an individual plan. I just received just prior to this a renewal for our insurance  
14 that informed me that our premiums are going up annually by 42% for this next year. So because I  
15 have them on private insurance, and my son is on private insurance with us, and this bill's coming  
16 through; it's as Ms. Findlay said, I feel like we're going to have to remove him and that this is going  
17 to have to become his insurance because we now are paying a premium for this, instead of billing it  
18 through our insurance first and doing it that way. We are seeing a significant amount of insurance  
19 increase that we are seeing there, coupled with what's going to happen with the Katie Beckett  
20 Program when we renew. But it could be a problem.

21 Another piece I wanted to touch on that someone mentioned was that Katie Beckett for so

1 many cases, and our son is very young. We caught what he had and got him into the system so  
2 quickly that the early intervention for him was crucial in getting him started in successes and  
3 helping him to learn. So he's three (3) years old now and he's starting to talk a little bit and doing  
4 some things like that. But the momentum has, where transitioning came into a school program  
5 now, and as we talk specifically in his IEPs with his teachers, and we are concerned about  
6 momentum and how to keep all the skills he's learned over the summers and you know to keep him  
7 progressing, that this transition to a fee-based system may potentially damage or set people back  
8 because they might consider removing from the system, and where they had done so well and there  
9 kids are progressing, but this may be a hindrance to them. So I'm concerned that the fee structure,  
10 as aggressive as it is in percentages, is too high. And I think it's been hit several times that it needs  
11 to be reevaluated specifically from even with the jump from into that 3% to the 4 ½% on how those  
12 are done and if there isn't a better graduated system if a fee has to be collected that is not as  
13 aggressive so that it gives those parents a chance to keep their kids in there and find ways to make  
14 up the difference, because Katie Beckett, as I think we can all agree, has been a great program for  
15 all of our children, but something we have come to have as a security in some cases because we  
16 know that it will help us. And now to have it change like this so suddenly, and for some people  
17 renewing right now, it's too much of a burden. And I think it really needs to be reevaluated, and the  
18 methodology of how they are going to bill or how they are going to determine what the cost is  
19 needs to be reevaluated. Thank you.

20 *TIM GERLITZ:* Would anybody else like to testify? Say your name please and spell your  
21 last name.

1           *DENISE WETZEL:* Denise Wetzel. W-E-T-Z-E-L. And I just have a couple of comments  
2 to make. First, I kind of feel this is almost discrimination against people who have children on the  
3 Katie Beckett waiver. I mean, why is Medicaid picking on us? We are a, as it has been mentioned  
4 several times, how a burden of having a child with a disability. I have two children on the autism  
5 spectrum. I did not have to ask these children with these disabilities and we are trying to do the best  
6 we can. And as many people, my husband lost a job last year, and now I've tried to find part-time  
7 work which is almost impossible because I have to kind of work from home, and to find something  
8 that's flexible enough that I can take care of my children and get them to their appointments; their  
9 occupational therapy, their speech therapy, here and there for that program, and everything. It's  
10 very difficult. So it seems like another kick to our budget a little bit. I actually consider my  
11 youngest child to be a success story of Katie Beckett because he got such great early intervention.  
12 And he was like two and a half (2 ½) and was barely putting two words together and now you can't  
13 get the boy to shut up. And he's a delight. And he's made so much progress just because of his  
14 intensive behavior intervention that he's gotten through the Katie Beckett Waiver. And I kind of  
15 worry, because I am such a big proponent of the early intervention, that once the word gets out to  
16 people that if you apply for Katie Beckett you're going to have to pay so much a month. I'm kind  
17 of worried people will hesitate and they won't do it. Then, there are going to be a bunch of children  
18 out there that aren't getting the services they need at an early age and they're going to become, you  
19 know, they might get better, they might not, and then they're going to be more of a burden later on  
20 because they didn't get the critical early intervention that would have been so helpful for them.  
21 And I guess that's all I have to say. I just kind of feel like it's discriminating against people who

1 have children on the Katie Beckett Waiver. And I don't know if Medicaid is planning to do this for  
2 other services, the fee-based system, but it seems like I don't know why they're picking on us kind  
3 of is my question. Thank you.

4 *TIM GERLITZ: Anybody else . . . . (Inaudible.)*

5 *SARAH GARCIA: I need to respell it? Okay. My name is Sarah Garcia, and I would just*  
6 *like to circle back on a couple of comments regarding alternatives for if the State is looking at a*  
7 *dollar figure or whether it's a cost-sharing initiative that they're striving for. Whether it's the*  
8 *principle of the cost-sharing or whether the principle is the dollars. I just did, I'm sorry, I'm a*  
9 *numbers person, I do that for a living. I did a quick calculation based on the comments of four*  
10 *parents and the premiums of those four parents in this room is more than 10% of the \$210,000*  
11 *savings the entire State is striving to find. I can't believe that those five parents in this room are*  
12 *10% of the Katie Beckett population. I think it's just an example that it's almost a taxation. It*  
13 *actually is a taxation. It's not cost-sharing. It's a way to get, it's penalizing the parents severely.*  
14 *The parent, I apologize for not learning anybody's name, who mentioned that there is abuse in the*  
15 *system, I agree. I would love to see what it's costing the State to provide my son's services that he*  
16 *gets. I would maybe feel better about this 3 or 4% if I had any idea the value of the services he was*  
17 *getting, and also to know whether services are being attributed to him that he's not receiving.*  
18 *Because as everyone mentioned, we know there's inherent issues in medical billing processes, and*  
19 *we should be looking at the people who are creating abuse, and the suppliers who are creating*  
20 *abuse. And the people, you know, those of us who need this waiver and who need our children to*  
21 *develop, and want our children to develop, to penalize us when we're the ones trying to do the right*

1 thing doesn't feel right. We should try to figure out who isn't doing the right thing and get that  
2 straightened out rather than force us to potentially go into bankruptcy and become other, be  
3 dependent on the State in other ways. And the other thing I would like to say is just because I have  
4 a larger income doesn't mean my son has great disabilities as well, but his disabilities are not a  
5 reflection of my income. It doesn't work either direction. Just because I happen to have a small  
6 income doesn't mean my son has small disabilities or big disabilities. It shouldn't be about the  
7 income, it should be about the needs of the child and the abilities of the family. That is all I wanted  
8 to follow up with. Thank you.

9 *TIM GERLITZ: (Inaudible).*

10 *RASHELL PATTEE:* One other thing. It doesn't have to do with this ruling but it has to do  
11 with other cuts that have come about in the last year with the developmental therapy hours that have  
12 been decreased from 30 hours a week and the IBI hours that have been decreased from 30 hours a  
13 week to 22 hours a week. I would just like to say how that has impacted a lot of families who rely  
14 on services like this for care for their children while they try to work. I use the developmental  
15 therapy to help so that I can work outside of the home and be a taxpayer, and be able to contribute  
16 to taking care of my children, and feeding them, and clothing them. But I also would like to  
17 comment on how difficult it is to find daycare and people to care for our children who are qualified  
18 and understand our children, and are able to deal with their behavioral issues, and be able to teach  
19 them proper social skills. I have a sister-in-law who works at the YMCA in Idaho Falls. She is the  
20 director over the daycare facility there. With this particular cut that they've already done to the  
21 Katie Beckett Program, she has seen more parents seeking a need for daycare. She cannot take a lot



1 of these children on who come into her facility. She has tried and she has had to turn them away  
2 because her staff and her abilities are unable to deal with the children that have disabilities in this  
3 regard. It is a very difficult thing. If I had to choose to work more and pay for daycare, we're  
4 talking \$1,000.00 a month at least to do full-time daycare. Who will watch my kids? Will I be able  
5 to find someone to help me watch my kids to work more in order to pay for the costs that I need to  
6 accrue to be able to help pay for the Katie Beckett rule changes? But I just wanted to let the State  
7 know that this just doesn't affect only the Katie Beckett families. It affects the facilities who have  
8 to turn away children who they cannot help care for because they don't have the ability. It's not  
9 fair. It's not fair for parents who are trying to do their best. It's not fair for care facilitators to have  
10 to turn away people and feel guilty or inadequate to be able to help us. She would love to help, my  
11 sister-in-law would love to help these families, but she cannot tolerate cars being thrown at other  
12 kids, teachers that don't know what to do with them. It's not fair. It's one consideration that I will  
13 have to take in to be able to pay for this change. But it's also another concern for all these parents  
14 who need to be able to have someone to take care of their child if they choose to work out of the  
15 home and try to make the cost qualifications that have come to us. So it's just another part of this  
16 whole thing that we have to be able to consider I have gone through all kinds of considerations on  
17 what to do because the costs will be so great for my family, and I'm at a loss. And I just wanted to  
18 let the State know that it's not just affecting us, you know, it's going to affect everyone in the State.  
19 It will affect everyone. Thank you.

20 *TIM GERLITZ:* Anyone else want to testify?

21 *ED GRAY:* My name is Ed Gray. G-R-A-Y. I think a couple of points I wanted to make

1 was, and Ms. Pattee just talked about, is they are cutting services beyond the Katie Beckett  
2 Program. The IBI therapy hours are all getting cut. DDA services are being cut. And a lot of this  
3 goes beyond just diapers and medicines and things. It's a way of life. And if you look around this  
4 room, there aren't very many husbands and wives here. Just because it takes one parent. If they're  
5 lucky enough to have two spouses at home with a child with a disability, one of them is probably at  
6 home right now taking care of the child. It's hard to just go to a movie together. My son is almost  
7 seventeen (17), and my wife and I have probably been to four movies since he's been born and  
8 since he's been diagnosed with autism, because you just don't take him down to the ABC Daycare.  
9 It takes special people to take care of him because Cody has a lot of disabilities as far as behavior,  
10 seizures, and some other things. And it's actually very rare, I think, to see a married couple stay  
11 together very long because of the stress of having a child with a disability. So it's not just, you  
12 know, there's so many things involved: marital stress, family stress, the meds, the seizures, the  
13 worrying about the IEPs and ESYs through the school districts, but what gets me is the costs. One  
14 of the criteria, you know our son who qualified for the Katie Beckett Program, because without my  
15 wife and I, he would be in a full-time institution which is a lot more expensive than living in our  
16 home with us paying the utilities, and food, and everything else that goes along with it. It isn't  
17 covered by our private insurance or Medicaid. And if he had to go into ICFMR, there aren't any  
18 available. In fact, the Idaho State Hospital is reducing its number of bed right now. So it's easy to  
19 say, "Oh, there's respite care available." That's not the case. And just simple things as going to a  
20 movie, going out as a couple, or just getting time away and deal with the stress of your other job  
21 that you're keeping part-time, these programs save the State so much money in the long run, I think.

1 So I hate to see any cuts to them. The fee schedule is just extremely high for a lot of families.  
2 You're talking probably in some cases half of what they pay for monthly rent or more. So when  
3 you start making decisions like that, where do you go? It's not like you can just go get another  
4 because you still have a child at home to take care. So it's just very frustrating and I, you know,  
5 there's a lot of people that are worse financially than my family is, but the stress of raising a child  
6 with a disability is similar for everybody. Thank you.

7 *TIM GERLITZ:* Anyone else? Yes.

8 *KRISTIAN CARSON:* Kristian Carson, again. I just wanted to reiterate something that was  
9 brought up about caretakers. Especially in my situation being a solo single parent. There was no  
10 one that would take my son because of his behaviors. He was high functioning, but still low  
11 enough that he couldn't socialize with others. I didn't even know that he could have got a personal  
12 care person until, I think, I ran into another parent that had one and that was year's later. He's ten  
13 (10) now and I brought him here at three (3), and I've done it for seven years not on our own.  
14 When I was in between jobs, when I had the part-time job, it took another parent that had two  
15 children with autism to help me out because I couldn't find anyone else that could handle my son.  
16 Now, he's come such a long way, and I'm so thankful that he is not that young age again where he  
17 would need that intervention of IBI. He finally is to where he can be in a program. He's in a touch  
18 summer program. He has a DT. He can go out in the community now. He's come a long way.  
19 And Katie Beckett was a saving grace for me when they considered me over-income. And it wasn't  
20 by much, you know, I'm right on the borderline of that. So I want to reiterate how important that  
21 early intervention is and how parents would let their kids slide because the fear of that. And you are

1 going to have a problem later. At his school it was not easy to get them to let me have an IBI  
2 worker in the school district. Because he was having so many problems, they finally gave in. But  
3 my fear was that he was going to, they didn't want to do it then, their thing was, "Well, when he's  
4 fifteen or something, then we might be able to get you help when he's older." I didn't want to wait  
5 until my son became a problem that they would step in and then, you know, lock him up in a  
6 juvenile detention center because he's high functioning but then yet has behavioral problems, can't  
7 socialize. His third year of school, he's now going to be a fifth grader, but his third year, you know,  
8 he had quite a bit of relapses. I had to be gone from my job for about three weeks. I was gone a  
9 week, came back, gone another week, came back, had to leave another week for my job. My son  
10 relapsed and it took his IBI workers really coming together and pulling and getting him structured  
11 again that he came back. And he's doing fantastic. But it terrifies me, and I'm so thankful he's my  
12 only child. I can't imagine having another one right now that's three or four newly diagnosed and  
13 not getting that help, you know. He's talking, and he's smart, and he's active, and he's now got a  
14 little girlfriend down the street that he rides bikes and plays with. This would not have happened  
15 years ago. You know, he's finally becoming to where he's going to be a functioning adult. But  
16 that's if I can keep this going. He can't have after-school care in a regular program. He has a  
17 personal care person that has to be there because I can't. I'm one person. He has to have that. I  
18 know all these other parents, there are two parents and one's making the sacrifice, you're on one  
19 paycheck. And I just want to reiterate how important that little edge is to make us self-sufficient  
20 and to make us be there for our children, and also for us as people to function within this society. I  
21 mean, right now I can't imagine losing my job because I'd have to be there full-time for my son, or

1 cutting back part-time because I can't afford to take care of him, you know, take care of being there  
2 for him. I had to do it, thank God I was in school full time that I could be there, and I was taking  
3 internet classes, and I was up at 4:00 a.m. in the morning studying and getting classes done so I  
4 could be there to get him ready for school and be there when he was sick, and you know the weeks  
5 that he couldn't make it for school or when their on holiday I was there. But I mean that Katie  
6 Beckett portion got me through those little bumps. And I don't mind paying a percentage but my  
7 concern is how great a percentage that is. How great that they want to take this chunk out. And I  
8 see people abusing the system. There's abuse in the system and why that's not getting more  
9 focused on. For me to get any kind of help for him. The paperwork's sick. I have a file dedicated  
10 to just Cody, that long. And anytime he goes for a program or renewal, I have to bring everything  
11 out and show them yes, he has these needs. Why isn't other people that are going for disabilities  
12 having to prove that? I don't understand that, and I'm referring to Social Security in particular, that  
13 I don't understand why is it that we're so penalized and you have to prove, and prove, and go to  
14 such lengths to prove that yes, your child has a problem or a special needs. I don't understand that.  
15 And all I want to say is that, you know, for these people that have younger children that need that  
16 help, I just can't imagine them getting slapped in the face like this. And as she said it's a form of  
17 discrimination, that's just exactly what came to my mind. And that's all. I just want to reiterate  
18 that it is a useful program, and it is helpful, and it gets you through that bump. And I just wish that  
19 somebody would just say, "Let's take a step back and see." You know, how can you accomplish  
20 your goal of getting the money you need but doing it by being realistic about it. And that's all I  
21 wanted to reiterate.

1           TIM GERLITZ: Yes. (*Inaudible.*)

2           KAREN WALLIS: Karen Wallis. So I listened to everybody out there and it seems to me, it  
3 appears anyway that the schedule states that the low end is like \$15.00 a month. It doesn't appear  
4 that most of the people here fall into that category. It appears in listening to most people that they  
5 fall into the 3 to 4%. And I think, what I wanted to reiterate was, you know \$15.00 a month might  
6 be a lot to some people, and I agree, and most likely, and I'm just making a statement, that many of  
7 those people may be having to use the system in other ways also. We are a family that falls into the  
8 3 to 4%, and I think that's hitting us particularly difficult in that range because we go from \$15.00  
9 to several hundred dollars. And that hits a family hard. We have more income. It is not more  
10 disposable income. It's just more income. We're very fortunate, and I think the State should look  
11 at it as fortunate, because we are able to pay more costs on our own. Like I said, in our situation  
12 our son just entered Katie Beckett a year ago. He's fourteen (14) years old. And so for thirteen  
13 (13) years, we solely paid for everything with our child. And we are middle-class America. And  
14 we have done diagnostics, we have had huge bills. We have no savings, very little savings. You  
15 know I listen to the economy and I listen to people talk about how to save some money and it just  
16 angers me to hear people say, "Well, you know, if you quit getting one latte a week you can save x  
17 number of dollars." That just angers me because I don't get a latte everyday. I don't get these  
18 things because I pay a lot of money for meds. My child's on three different medications that if you  
19 took him off of it, there would be heck to pay. And we don't skip nights out to dinner because  
20 that'll save money because we aren't out at dinner every night, because we have to make sure that  
21 our child has a strict diet. We spend a lot of money on food every night. Our food bill is huge. But

1 we make sure that our son has what he needs to function at optimum levels. And so, I'd like to say  
2 that, you know, I think the State really needs to look at the people that are really affected appear to  
3 be people that have enough income in their eyes obviously because their looking at this like, "Oh,  
4 well you make a high income. You can pay for it." Well I agree, and we have spend thirteen years  
5 doing what we felt was beneficial for him. And we have spent thousands of dollars. I call him my  
6 million dollar child, and I mean that, but I love him immensely, and he's here listening to all of this.  
7 And you know, but the thing is is that we have very legitimate health issues and very legitimate  
8 disabilities, and just because we have a certain income level, as do all of you most likely, I think the  
9 State needs to realize that we also have a lot of debt because we're doing the best we can for our  
10 kids. And \$15.00 is one thing, but several hundred is devastating to most of us. And so thank you  
11 for letting me re-speak.

12 *JILL SMITH:* Hi, I'm Jill Smith. And I apologize in advance for probably talking in sound  
13 bites, but a couple of things, I have to admit I'm really nervous. I'm even more nervous now than I  
14 was when I came in because like I said, I have a very short amount of time to actually, and I will be  
15 in this process of having my co-pay established. And I would really hope that the person who's  
16 assessing me and my budget knows more about this than I do. So I am very concerned about that. I  
17 wanted to mention that I know Katie Beckett often times is looked at as a very expensive program  
18 because there are very cumulatively high needs kids in the program. A friend of mine had a child  
19 who lodged a fishing lure behind their ear and this child has autism, so they went to urgent care and  
20 was told, "We're not touching your child so go to another clinic," and ended up in the E.R. where  
21 rates are a gazillion times higher, because they would not serve a child with autism at a lesser level

1 of care. So, throwing that out there, again, that's one of those discrepancies between what a child  
2 with a disability can access versus what a child without a disability can easily access, and the costs  
3 are higher. Not by our design but by the system's design. It scares me very much to hear some of  
4 you talking about giving up your commercial insurance, because there is a huge hurdle if you do  
5 that. When you walk into a doctor's office, and you might have been given a leather coat by your  
6 parents who think you're nice and it was on sale, and you drove an SUV, and you walk in and hand  
7 over a Medicaid card, you are treated like you're exploiting the system. And obviously you must be  
8 because you don't look like you're poor, you don't look like you're indigent. So how can you  
9 qualify for Medicaid? And you're treated terribly, if you can get in the door at all with only  
10 Medicaid. I know of a family that drove to Lewiston for a dental appointment because no dentist in  
11 town would take them with Medicaid only. So, when Cameron spoke of having a 44% increase in  
12 his insurance and they might have to get rid of that, it scares me because they won't be able to  
13 certain providers in this area. It already takes six or seven months to get into a child neurologist, if  
14 you're lucky. If you have Medicaid, you can sit in the doctor's office like I did with Dr. McDonald  
15 from Sacred Heart, who is wonderful and he is great, and for a half of an hour of a \$400.00 visit to  
16 check Alex's vegas nerve stimulator, I heard him complain about the burden they had because of  
17 how many people in their caseload have Medicaid. And the State pays for that tirade. If you give  
18 up commercial insurance, you're at the mercy of providers who say, "We will not take you." And  
19 then what? You end up in E.R.s and hospitals and children's hospitals in Seattle and in Utah  
20 because you can't get care anywhere else. So that was one of my comments about insurance.

21 The other thing that's kind of a silent statement, and I'm assuming some people will nod



1 their heads when I say this, it is not like our school system is a stop gap for a loss in services or an  
2 inability to access services on our own and privately. Alex hasn't gone to school full-time since he  
3 was in preschool. He can't function long enough to be in school. And in the last two years it hasn't  
4 worked at all. And so the school system, when you go in for an IEP and you get to the service page  
5 where it says who's going to do what when? They talk in Medicaid terms. They don't even say,  
6 "We would like to serve your child for five days a week." They say, "For developmental therapy,  
7 we'll provide this many units, and for this we'll provide this many units." And if you're not signed  
8 up for Medicaid, they do their darnedest to get you to sign up for Medicaid because they need the  
9 income. Again, that is, these things that I'm talking about are an example of how the system is  
10 broken, and it's, again, I don't think we know all the answers to this, but if my premium is  
11 generated off my gross income, then I'm going to be taxed on money that I am being on this  
12 premium. I would assume that somehow the State would say, "Oh no, that \$500, \$600 that you're  
13 paying is exempt from your taxable State income." But what if it's not? And so, then I make this  
14 amount, I take this amount out, and I'm still taxed on the whole caboodle? That doesn't make  
15 sense. So I'm assuming that somebody thought of that. But if nobody thought of that, in a month  
16 I'm going to have a premium payment. This isn't right. And to the Pattees, if I'm saying that  
17 correctly, I am so glad you brought up the issue of multiple children. When I got the letter I  
18 thought, oh, well there is no way. I know a people who have three kids on Katie Beckett. There's  
19 no way they'd do multiple premiums. I don't know that they're not thinking of doing that. And  
20 that is repugnant. The idea that a family would pay three sets of premiums because they have three  
21 children who qualify for a developmental disability program. That's just not right, but there's

1 nothing in this language about exemptions like that. So again, I just reiterate my statement that  
2 before we go any further down this road, people need to come up with a much better way of  
3 assessing, other than a two page statement with one line that says, "What is your gross monthly  
4 income?" That's all I have, and it's in my purse. So, there's got to be more to it than that. Thank  
5 you.

6 *TIM GERLITZ:* Once again, there is a restroom out this door... (*inaudible*). Anyone else  
7 like to testify?

8 *MATT HOWARD:* Matt Howard. H-O-W-A-R-D. I'm glad that the subject of two  
9 children came up. We both have, excuse me, we also have two children in the system and if the  
10 case is per child, then we're going to have to make the decision which one deserves it more. So the  
11 case of robbing from Peter to pay Paul, we have to make that decision. I'm greatly frustrated with  
12 the amount of information on a short term that we received on this. All these questions are coming  
13 up and we do not know even the start of the answers. And some people have to start paying  
14 without even knowing the answers. That's pretty much what I have. Thank you.

15 *TIM GERLITZ:* (*Inaudible... .*)

#### 16 **CLOSING STATEMENT**

17 *TIM GERLITZ:* This hearing, having been called, commenced at 7:00 p.m., and it is now  
18 9:00 p.m., and is now closed. The record, together with the exhibits, will be transmitted by me to  
19 the Administrative Procedures Section of the Department of Health and Welfare. Anyone wishing  
20 to submit further comments should address them in writing to: Tamara Prisock, Department of  
21 Health and Welfare, Administrative Procedures Section, 450 West State Street – 10<sup>th</sup> Floor, P.O.

1 Box 83720, Boise, Idaho 83720-0036. All written comments must be received or personally  
2 delivered to the Administrative Procedure Section by July 22<sup>nd</sup>, 2009. And that concludes the  
3 hearing.

#### 4 **CERTIFICATION OF TRANSCRIPTION**

5 The undersigned does hereby certify that she correctly and accurately transcribed and  
6 typed the above transcription from the recording of the public hearing to the best of her ability as  
7 provided in two (2) cassette tape audio recordings. Said hearing took place in Coeur d'Alene,  
8 Idaho.

9 There were places on the recording that were not clear due to individuals talking over  
10 each other, coughing, or what was said could not be understood. Additionally, Mr. Gerlitz was  
11 not at the microphone during places in the hearing and could not be heard. The places that were  
12 not clear enough to accurately transcribe are marked on this transcript as "*inaudible*".

13  
14 Dated and certified to this 27 day of July, 2009.

15  
16 \_\_\_\_\_  
17 Tamara L. Swanson